

Chronic Pain in MS

Do you, or someone close to you with multiple sclerosis (MS), have pain that has lasted for more than 3 months? If so then this article is written for you.

Chronic Pain is defined as pain that is continuous or reoccurring for 3 months or longer. This article aims to provide you with information on some of the chronic pain syndromes that occur in people with MS and the options available to manage these syndromes.

Chronic pain is a problem for over half of all people with MS at some time in the course of the disease¹. Approximately one in five people with MS experience pain at the onset of their MS and for some people the pain continues as a long-term symptom. About a third of people with MS report that pain is their most severe symptom. The incidence and severity of pain is not related to the age at onset of MS, type of MS or degree of disability.² Pain syndromes are however more prevalent after the age of 60 years and with increasing length of time the person has MS².

Chronic pain syndromes can occur as a direct result of MS or from unrelated causes. The chronic pain syndromes that occur because of MS can be divided into two categories according to where the pain originates:

1) **Central Neuropathic Pain** can occur as a result of damage to nerves in the brain and spinal cord, also called the central nervous system (CNS). In MS the nerves in the CNS are changed by loss of the insulation cover (the myelin sheath) and messages being sent between the brain and spinal cord are disrupted³.

Central neuropathic pain⁴ is often associated with loss of sensation² and some unusual features such as the feeling of pain with normally painless experiences⁴. Touch, movement or even a breeze, may be felt as pain and this is referred to as allodynia⁴ or hyperalgesia. Chronic central neuropathic pain syndromes include dysaesthetic extremity pain (burning type pain in the leg or arm), some back pain syndromes and some visceral (abdominal) pain syndromes.

2) **Nociceptive Pain** comes from body tissues (except nerve tissue) that are disrupted or distorted as a consequence of another symptom of MS. Nociceptive pain can arise from muscles, joints, skin and some internal organs. This is the type of pain you feel when you have joint or muscle sprains, cuts, abrasions or stomach upsets. Chronic nociceptive pain syndromes that arise from other symptoms of MS include some back pain syndromes, some knee pain and pressure area pain.

A person with pain, irrespective of the cause, will have a different experience of the pain and react differently from another person who has similar pain. This is the affective component of pain and it may be influenced by many aspects of a person's life such as their previous experience of pain, their sense of well being as well as the social, family, cultural, emotional and spiritual aspects of their lives^{4,5}. The affective component of pain is used in some management options to reduce the impact of pain on a person's life.

(cont. in Spotlight - p9)

TELECONFERENCING



Teleconferencing is a great way of linking people, over great distances to meet and exchange information. The best part is that participants can relax in their own home wearing their PJ's sipping their favourite beverage and nobody is the wiser. In April a teleconference on Fitness and Exercise was

run for the Bega Support Group and was well received by all participants. Katrina Williams MS Society Senior Physiotherapist, talked about the benefits of exercise for fitness and how exercise can increase stamina, strength and suppleness resulting in an increased ability to endure doing an activity for a longer period of time. Katrina also explained that exercise can decrease the risk of coronary heart disease as well as change our rate of metabolism to help reduce the risk of obesity and to top it off it can delay the physiological effects of aging - what a bonus. It is helpful in increasing self confidence and a feeling of well being by reducing stress and depression.

Barbara Whitelaw Outreach
Worker South Coast/Goulburn
Region



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Author of “Chronic Pain” (Page 1) Robyn Smith is a physiotherapist with the MS Society of NSW. Prior to coming to the MS Society Robyn worked at the Northside Clinic's former Pain Clinic. She graduated with a Diploma in Physiotherapy in 1975 and completed a Graduate Diploma in Educational Studies (Health Education) in 1982. She is presently enrolled in the Masters in Health Science (Neurological Physiotherapy) at Sydney University. This course enabled her to study pain in multiple sclerosis and develop the article in this edition of MagScene.

Robyn presented one of 7 posters from the MS Society of NSW at the Multiple Sclerosis International Federation Conference in Melbourne in 2001. The poster entitled 'Symptom Change with Exercise is a Temporary Phenomenon for People with Multiple Sclerosis' won a prize for the best poster. That prize was a trip to Chicago for the Consortium of Multiple Sclerosis Conference. Robyn has just returned from this conference where she presented a paper on the study. It was an opportunity to share the study with health professionals and people with MS worldwide.

The article and poster were possible thanks to the efforts of many people with MS, health professionals and staff of the MS Society of NSW especially in rehabilitation services.

As for personal details, Robyn is married with three school age children and apart from family and school interests, enjoys walking, golf and reading. Ed.

COLONIAL FIRST STATE FUN RUN / WALK FOR MS



Supporters: - stride, jog, sprint, lope, stroll, march, saunter, amble, pace, scuttle to support people with MS

About 2,500 people took part in the twelfth annual Colonial First State Fun Run/ Walk for MS on Sunday June 2.

The event seeks to raise \$100,000 for the support of people with MS.

Approximately 400 runners took part in the 8km Fun Run up to Balls Head return and 2,000 participants walked in the sunshine from Milson's Point to Sydney Eastern Suburbs. taking in stunning views around Sydney Harbour foreshore. The 10km walk course went through Rushcutters Bay where North Sydney Boy's High school

performed live jazz music during a morning tea stop. Walkers then had the option of finishing at Steyne Park, Double Bay where the NSW Police Band provided live entertainment or continuing

on to Watsons Bay to complete the 20km course.

Karl Kinsella, MS Outdoor Events Manager said: "The mass start was a spectacular sight. The fact that triple Olympian walker Kerry Saxby-Junna led out the field created a great buzz among participants that lasted all day."

"There were over 200 volunteers scattered along the route. These people give up their time to ensure participants have a safe and enjoyable day. We could not run any of our outdoor events without them and we cannot thank them enough."

"We would like to thank everyone who took part on Sunday and supported people with MS".

To date the event has raised over \$560,000 to help people with MS.



The "Milo Milers" raised the highest amount.

PENSIONS, BENEFITS AND ALLOWANCES

We have been asked to collect information on pensions, benefits and allowances possibly available to PwMS.

We present it in a form that we hope is easily understood. We will give some Internet sites that are useful as well as giving a shortened description of each pension or allowance.

Disability Support Pension

Disability Support Pension - for people unable to work for 2 years due to illness, injury or disability. The Disability Support Pension is a payment for people whose physical, intellectual or psychiatric impairment prevents them from working, or for people who are permanently blind. (May 2002 single adult payment is \$421.80 with married or de-facto \$352.1)

http://www.centrelink.gov.au/internet/internet.nsf/payments/disability_support.htm

Wife's Pension

Eligibility: wife of a disability support pensioner who is not eligible for a pension in her own right.

Sickness Allowance for people temporarily unable to work due to illness, injury or disability.

It provides assistance for people who are employed and who are temporarily unable to work due to a medical condition. In some situations, full-time students may also qualify for Sickness Allowance. Sickness Allowance is not a long-term payment. It is only paid for temporary incapacity for work or study. The commencement date for

Sickness Allowance is affected by the payment of sick leave, annual leave and other leave payments made by the employer. Self-employed people may receive Sickness Allowance if they intend to resume their employment when they are fit to do so.

<http://www.centrelink.gov.au/internet/internet.nsf/ea3b9a1335df87bcca2569890008040e/4ccab94c64ee4b9bca256a3f001aa6be!OpenDocument>

Carer's Assistance

Are you caring for someone who is frail aged, ill or has a disability? If you are caring for someone who is frail aged, ill or has a disability Centrelink can help. http://www.centrelink.gov.au/internet/internet.nsf/individuals/carers_index.htm

Mobility Allowance

Proposed changes to the Disability Support Pension, may result in some people with disabilities losing access to a Health Care Card and associated benefits. A way that people with disabilities can access a Health Care Card is by applying for Mobility Allowance. This is only available when the person with a disability is performing more than 8 hours a week of paid or voluntary work, or recognised training. It is also available while looking for work. That's right – even if your MS has not yet forced you to shorten your working hours there may be government assistance (May 2002 payment is \$64.40 per fortnight) A Health Care Card, entitles you to cheaper medications. To medically

qualify for Mobility Assistance you must be unable, *without substantial assistance*, to use Public Transport. A medical report certifying this must be filled out by your doctor and must accompany your application. The required form is available from Centrelink, and can be completed by either your GP or Neurologist. Once you have been awarded Mobility Allowance, if your condition has been assessed as permanent, there is no further medical assessment required.

Special Benefit

Eligibility: people in financial hardship and unable to earn a sufficient livelihood for themselves and their dependents, not eligible for some other pension or benefits.

Child Disability Allowance

Eligibility: parents and guardians, in addition to family allowance, for a child with a disability who requires substantially more care and attention than other children of the same age (must be medically assessed). Not payable for a student aged 16 - 24 in receipt of a Disability Support Pension or for a person in receipt of a Sole Parents Pension.

Veterans: Pensions, Benefits, Allowance and Services

Australian and allied veterans, war and defence widows and certain dependants may be assisted by compensation and welfare pensions, allowances, treatment aids and appliances, counselling services, and housing loans.

Domiciliary Nursing Care Benefit

If you care for someone who has been assessed as requiring "nursing home" level of care (i.e. assistance with bathing, dressing, eating, toileting and mobility), you may be eligible for the DNCB. The person you care for must be over the age of 16 years and have a long-term illness or disability. Application forms can be obtained from your doctor, local nursing organisation or Department of Health, Housing and Community Services. The benefit is not means tested, is tax free and separate from other benefits provided through Social Security or other Government Departments.

Medical Expenses Rebate

A rebate is available to a taxpayer whose net medical expenses in the year of income exceeds a certain amount. Inquiries should be directed the Taxation Office. All areas are listed in phone book under Australian Taxation Office

Continence Aids Assistance Scheme (CAAS)

A Commonwealth program offering assistance to people who have permanent and ongoing incontinence as a result of a neurological condition or severe intellectual impairment.

The aim of CAAS is to help eligible clients meet the cost of continence aids. Intouch (formerly PQ Lifestyles) operates the CAAS under contract to the Commonwealth Government and clients currently (June 2002) receive a subsidy of \$465 per year on continence aids ordered through Intouch,

Intouch can give you advice regarding your eligibility. Phone Intouch on 1300 366 455

Isolated Patients' Travel and Assistance Scheme (IPTAAS)

The NSW IPTAAS program provides financial assistance towards travel and accommodation costs incurred by patients who are required to travel more than 200 kilometers distance for specialist medical treatment. Financial assistance is also available for a carer in the case where the referring doctor certifies that an escort is required for medical reasons.

You should contact the IPTAAS office nearest you to check on your eligibility before undertaking travel. Albury (02) 6058 4498, Bathurst (02) 6339 5312, Broken Hill (08) 8080 1432, Dubbo (02) 6841 2279, Goulburn (02) 4823 7805, Lismore (02) 6620 2168, Tamworth (02) 6766 3946, Taree (02) 6592 9299

Suggested Internet sites are:

www.centrelink.gov.au
www.health.gov.au/acc/continence/caas.htm
www.carersnsw.asn.au/facts/fsiptaas.htm

If you have an MS Society Outreach Worker in your area she or he will be able to give advice on any of the above mentioned items.

The information above is not comprehensive; please contact your local CentreLink office for information on other Government assistance such as student allowances etc.

FROM THE DESK OF MS BUSYBODY

O-What-A-Feeling!!

- During the past two months I have met several generous individuals who have positively uplifted my spirits. They were each dedicated to fundraising for MS. When I questioned the reasons for their benevolence, the answer was sadly, in each case that a friend had been recently diagnosed with MS.



In May, David and Rachael McDonald organised a gala dinner at Gosford for one hundred and fifty guests. They donated luxury items from their shop, 'Affordable Quality' then persuaded other businesses to donate goods, holidays and vouchers to be auctioned at the dinner.

In June, the MS Society benefited from an auction of paintings by artists Yianni Johns and Steve Preston. At the exhibition, when I was admiring Yianni's work, I told him that I was once an artist and my style was similar to his. I told him that thanks to MS, I'm not a poor struggling artist anymore. He was concerned when I told him, "Now I can't even hold a brush."

Steve Preston revealed to me unashamedly that inspiration for his zany artwork came from drug-induced-insanity. He was rescued by his friend with MS. He told me that now he has recovered (sort of), this is his way of saying 'thanks mate'.

.....**O-what-a-feeling indeed,**
- my new motorised wheelchair has elevating footplates!!!

Ms Busybody



LETS TALK

Because of much improved diagnostic methods (e.g. MRI) doctors are able to give a firm diagnosis of MS much earlier than in past years. This has the effect that there are now more younger people receiving a firm diagnosis than before. This means that the Society registers more young people every month.

There are, in NSW, thousands of PwMS aged from 40 to 60 so it is quite easy to find someone your age and with your interests. The same is not the case for younger PwMS.

Below I list a few of the young PwMS (below 30) who have contacted Lets Talk. I repeat them because the younger newly diagnosed may have missed them when they first came out. Remember if you would like to correspond with any of those listed below please send me an email (garrya@msnsw.org.au) giving the reference in question and I will send the address.

Coded Reference	425	Female
Age	27	
Lives in	Moree	
Years with MS	4	
Dated	2000	

I am on Betaferon and am doing OK. I would like to meet/talk to other MS people.

Coded Reference	454	Female
Age	24	
Lives in	North Shore	
Years with MS	2	
Dated	June 2001	

I would love to have a webpal close to my own age. My MS has not affected me much and I work full time (12hr days!!) and proud of it. I have a few balance problems. Look forward to hearing from you.

Coded Reference	456	Female
Age	28	
Lives in	Sydney	
Years with MS	1	
Dated	June 2001	

My first symptom was optic neuritis in Sept 2000. My next was a loss of my legs in Sept 2000 which was accompanied by my diagnosis. I've recovered 95% from both attacks. I'm a food technologist and have a real interest in diet and MS after reading about the possible links. I do not currently take any immunotherapy, I have however had methylprednisolone twice. I go to the gym 3 times a week and dance classes weekly. I work in North Sydney. I'd love to have someone to talk to in a similar position.

Coded Reference	469	Male
Lives in	Sydney	
Age	22	
Years with MS	6months	
Dated	January 2002	

I'm a 22 year old (23 in January 2002) who was diagnosed about 6 months ago. I'd be very grateful if you could put my details in Lets Talk. I'd love to chat with other people my own age who have MS. I have yet to find anyone around my own age and am having a hard time dealing with things.

Coded Reference	470	Female
Lives in	Sydney	
Age	21	
Years with MS	5months	
Dated	January 2002	

I am currently about to enter my fourth and hopefully final year of university as an early childhood teacher. I live at home with my parents and have an older brother and sister who are both married from which I have one nephew and two nieces. I would love to talk to anyone with MS but particularly people my age to discuss how they cope and life in general.

Coded Reference	473	Female
Lives in	Sydney	
Age	23	
Years with MS	6 months	
Dated	March 2002	

I was diagnosed on 10th October 2001. I had lost all feeling down my left side and thought I was having a stroke. That happened on the 29th September. It was my mother's birthday. I spent 4 months in hospital and regained the use of my left arm and hand, but I still don't have the full feeling back. My left leg still doesn't work so I am in a wheelchair. I was asked out by my fiancé while in hospital and he proposed on February 14th. I would like to get in contact with others my age who have MS.

If you are thinking of connecting to or changing an Internet Service Provider (ISP) then you may be interested in the following address which give details of all ISP's in Australia.
www.cynosure.com.au/isp/

Another interesting website for those worried about claims of cures for MS is QuackWatch
<http://www.quackwatch.com/01QuackeryRelatedTopics/ms.html>

Garry

SUPPORT GROUP? NO WAY, NOT ME!

The first time my wife and I went to our local Support Group meeting, I was more than a little apprehensive, cautious, wary, frightened, all of those and more.

I was probably expecting to see people with all sorts of terrible disabilities, in wheel chairs and using all sorts of aids, with carers helping them and tending their needs.

I was sure that the degree of MS disability that I was used to was going to be made worse just by mixing with people who were worse.

I think I was scared stiff of seeing into the possible future. Of seeing what might be, or what might not be.

I remember, on the way there in the car, wanting to turn around and go home. We didn't really need to go to this silly meeting. It was that same feeling you get when you are going to the dentist.

Anyway, we plucked up the courage, put on brave face and went to the meeting.

We walked into the room to be greeted by a mob of friendly, smiling faces, sat down and started chatting about everyday things. Of course, the weather talk was a good starter and one thing led to another, you know how folks just ramble on. I must admit the women did most of the talking I just sat and listened!

We have made some nice friends at our meetings, PwMS's and their partners, wives, husbands, friends and relatives or whoever wants to come along.

Sometimes at our meetings, we have someone from the MS

Society, a Social Worker or Medical person, come along and give us some helpful advice or just talk to us on a variety of subjects or just talk.

Most of our meetings are held informally, in a restaurant, or similar meeting place.

It's nice to be able to ask someone sitting next to you, "How long have you had MS", and then swap life stories and such, if you want to.

When we need someone to talk to, when we are feeling a bit down in the dumps, when the MS is playing up, it's nice to know, that we know a few people in a similar situation who understand the problems that are facing us and can be our help-line and vice-versa. I think that is what Support Groups are all about.

My wife and I now look forward to going to our Support Group meetings. All the fears and doubts have gone. It's great meeting up with friends and having a chat.

We now know, that a Support Group is just simply that. It is there to give some support to us if we need it and we can also be supportive to anyone else if they are in need.

Go on give it a try. It's not compulsory, but is fun and it's better than watching the TV.

I can imagine just how my wife must have felt, going to that first meeting. She most probably felt a lot worse than I did, although she didn't show it.

Because, the thing is, it's not me that has MS. It's my wife that is the PwMS.

John R, - Orange

Some readers may already be aware that the LIS has re-located to the MS Study Centre at Lidcombe.

We have taken over the foyer and the collection of books, videocassettes, audiotapes, pamphlets and brochures are all on display for you to browse.

At present there is some considerable disorder in the arrangement but with the help of the LIS Volunteers, who have generously agreed to accompany the service to the new location, all will soon be in immaculate order.

The MS Information Line stays the same at 1800 042 138

These have been great changes in a very short time so please be patient as we gradually get organised and everyone becomes accustomed to working in altered circumstances. If you have made a request for information or a loan and not received a response within a reasonable time – say a couple of weeks, please contact the LIS again on our new numbers: 9646 0600 or 1800 069 159 (for country callers), fax: 9643 1486 and email is the same as before library@msnsw.org.au.

Or - of course - visit us in person in our new location at Betty Cuthbert Drive, Joseph St. Lidcombe.

Cate Dawson
Manager. LIS

FAREWELL KONNI KETTERITZSCH

Konni has been with the MS Society for over six years in the role of outreach worker in northern New South Wales. She was instrumental in establishing the Country north service and has played an invaluable part in meeting the needs of people with MS and their families in such a vast geographical region. Konni has also been active in delivering the newly diagnosed teleconferences and implementing a wellness-oriented information program to local support groups.

We wish Konni and her family every success as they resettle in Darwin, Thank you Konni.

Alex Hope, Acting manager,
Northern Region.

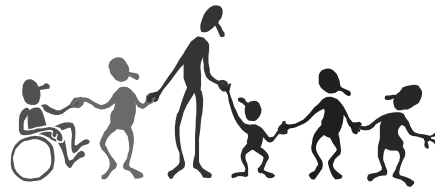
NEW OUTREACH WORKER FOR COUNTRY NORTH

Penny Kelly, a registered nurse who has an extensive professional background in primary, community and residential nursing care is the new outreach worker in the Country North Region. Penny has experience in nursing management and occupational health and safety and brings a wealth of experience in liaison with medical practitioners, health professionals and local community service providers.

She will be based at the Coffs Harbour Office.

Until further notice please direct all Country North clinical inquiries and client referrals to Shelagh Simpson at NRC (02) 9411 4522.

THE AUSTRALIAN PWMS “GET TOGETHER” 2002



This year the Australian PWMS “Get Together” is to be held in Canberra during the weekend of 20th to 22nd September 2002.

The itinerary will be similar to last year which encompasses a weekend of fun and fellowship includes, a “meet and greet” on Friday evening, and a semi-formal dinner on Saturday evening. The theme this year will be, “Adapting to Life with MS”.

Essentially, a booking will be made at a central location in Canberra for those requiring accommodation. Alternatively, those attending may seek their own accommodation. We are currently exploring the possibility of PWMS in Canberra providing temporary accommodation to other PWMS for this weekend.

The PWMS “Get Together” is a great opportunity for those individuals facing the challenges of living with MS to “get together” with their peers for a few days and “smile”. For more information, please contact Matthew on (02) 49366938 or Tracey on (02) 60241900

NEVER UNDERESTIMATE THE POWER OF A WOMAN

THE ROPE

There were 11 people hanging onto a rope that came down from a helicopter.

Ten were men and one woman. The rope was starting to fray so they all agreed that one person should let go because if they didn't, the rope would break and everyone would die.

No one could decide who should go so finally the woman gave a really touching speech, saying how she would give up her life to save theirs, because women were used to giving up things for their husbands and children, giving in to men, and that after all, men were the superior sex and must be saved. When she finished speaking, all the men clapped.

Have you noticed how you pick something up (usually small) and go to put it down somewhere else and it isn't in your hand anymore, forgot to watch what you were doing didn't you and have to go back to where you started.

Light travels faster than sound. That's why some people appear bright, until you hear them speak.

Everyone has a photographic memory. Some don't have film.

(Continued from front page)

WHAT CAN BE DONE ABOUT CHRONIC PAIN?

Chronic pain is a complex problem and is often difficult or impossible to completely eliminate. However, there are a number of options for managing chronic pain syndromes that can reduce the pain and/or its effect on a person's life. The management options that work for one person will not necessarily be tolerated or effective for another person with a similar pain. There is a range of options that apply to all chronic pain syndromes and these are listed below:

Non-Medication options include: exercise, warm or cold packs, transcutaneous electrical nerve stimulation (TENS)⁴, acupuncture³, relaxation, mental distraction, stress management¹ and psychological support².

Medication options include: anticonvulsants³ (such as Tegretol, Dilantin, Neurotin or Lamictal), tricyclic antidepressants² (such as Tryptanol, Allegron or Pertofran), intravenous Lignocaine² or sometimes narcotic analgesics⁴.

Pain Clinics: provide a wide range of specialized methods of pain management to improve quality of life with chronic pain. Examples include cognitive behavioural treatment or implanted drug pumps. Pain clinics are located in several metropolitan and country hospitals.

The following section describes some chronic pain syndromes in MS and provides more specific details of their management.

1) Chronic Central Neuropathic Pain Syndromes

Dysaesthetic Extremity Pain is the most common of several chronic central neuropathic pain syndromes as it occurs in up to 1/3 of people with MS and particularly in people with mild physical signs of MS². The pain can be burning, throbbing, aching or nagging and can occur in the arms or legs but is most frequent in the lower legs and feet. This pain is often worse at night or after prolonged activity. Dysaesthetic extremity pain is managed by some of the options for all chronic pain syndromes. The first choice of medication is usually a tricyclic antidepressant² and Capsaicin⁵ cream can sometimes help burning pain.

Visceral Pain Syndrome occurs in a small percentage of people with MS and is sometimes a central neuropathic pain. Symptoms of visceral pain syndrome include abdominal cramp, abdominal pain, aching and bloating². This pain is usually investigated to identify triggers such as urinary tract infection or constipation and treated with antibiotics and anticholinergic medication such as Ditropan². The

management options listed for all chronic pain syndromes also apply to visceral pain syndromes.

Back Pain Syndromes can be of central neuropathic origin^{1,2,5}. It can be differentiated from nociceptive back pain by the following characteristics: the perception of pain with usually painless stimuli, sensory loss, lack of effect of movement and posture on pain and ineffectiveness of simple analgesics and anti-inflammatory medications. The pain may alter with temperature change, exacerbation of the MS or at night. The range of management strategies for all chronic pain syndromes also applies to chronic central neuropathic back pain and similarly for chronic central neuropathic neck pain.

2) Chronic Nociceptive Pain Syndrome

Back Pain Syndromes are usually nociceptive pains and occur often in people with MS. Pain can arise from spasticity and tightness of the muscles in the back or from weakness of muscles and resultant changes in posture and movement patterns¹. The pain is usually increased by certain postures or movements and may present with pain down the legs. Management of chronic nociceptive back pain syndromes is directed at treating the contributing

PULL OUT
SUPPLEMENT

ON MULTIPLE SCLEROSIS
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factors to the pain, medicating for relief of pain (with simple analgesics such as Panadeine or anti-inflammatory medications² such as Nurofen) and applying the management options as for chronic pain syndromes as required.

When muscle spasticity is a contributing factor to back pain syndromes then it can be reduced by anti-spasticity medications such as Baclofen¹, Valium¹ and Dantrium⁵. Physiotherapy can provide exercises to strengthen the weak muscles², increase flexibility, improve posture and provide advice on movement patterns and mobility aids to reduce strain on the back.

The principles are similar for the management of other chronic nociceptive pain syndromes. The management starts with the treatment of the triggers of pain and the use of simple analgesic and anti-inflammatory and then if necessary the use of options for all chronic pain syndromes

Chronic Knee Pain from weightbearing on a weak, unstable joint for example will require strengthening, an assistive device for the knee and/or mobility aids to relieve some of the weight³. Medications are simple analgesic and anti-inflammatory and then some of the options for all chronic pain syndromes. *Pressure Areas* require normal pressure care and equipment to promote healing and then management as for all chronic pain syndromes.

Chronic pain is a common symptom of MS and a range of management options have been outlined in this article. Although it is often not possible to

completely eliminate chronic pain, effective pain management is available enabling people with MS and chronic pain to maintain satisfying lifestyles.

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(a copy of all references is held in the MS Society Library).

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Compiled by Robyn Smith, Physiotherapist, Rehabilitation Services MSS NSW for Postgraduate Studies at University of Sydney - Feb 2002.

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LATEST NEWS ON MS RESEARCH

Scientists and clinicians from around the world presented results of multiple sclerosis research at the 54th Annual Meeting of the American Academy of Neurology (AAN), held in Denver on April 13-20 2002.

Here we summarize some of these papers. This is by no means inclusive of all MS research presented at the meeting: Out of over 1,100 presentations, some 197 were related to multiple sclerosis or MS animal models.

The MS Lesion Project

Claudia Lucchinetti, MD (Rochester, MN) updated all AAN attendees on the progress of the National MS Society-funded MS Lesion Project during a special plenary session. This \$1.8 million, five-year project is a collaboration of top neurologists and pathologists around the world, led by Dr. Lucchinetti, to study lesions (damaged areas in the brains of individuals with MS) for clues to different patterns of destructive immune factors, and to correlate findings with clinical manifestations of MS and MRI findings.

Dr. Lucchinetti reported preliminary results from studies of brain biopsies (tissue samples) from 145 patients. Previously, she and her colleagues had found **four distinct types of lesions**, which differed in the pattern of myelin (the substance that insulates nerve fibers) and nerve fiber loss and in the activity of

immune cells and immune proteins. The team's data suggest that within an individual, the lesion pattern is the same, but that it differs between individuals. The investigators propose that lesion patterns may relate to disease type and possibly to treatment outcomes.

Data related to disease type are still being analyzed. However, one new finding relates to the team's analysis of lesion patterns in a small number of individuals who had received plasma exchange therapy, a blood-cleansing technique that has been used for severely progressive MS. They found that those whose lesion pattern included immune proteins known as "antibodies" were more responsive to plasma exchange therapy, while those without such a lesion pattern were less responsive. These data suggest that different patterns of tissue damage in the brain may be responsive to different kinds of treatments.

Future studies in this five-year project involve tracking individuals who had had brain biopsies taken in the past to determine current clinical status, and following them to determine if patterns of tissue damage are reflected in MRI scans. In fact, in preliminary analysis, people with another pattern of lesion, which involves immune cells known as macrophages, showed findings on MRI that were distinct from other participants. Dr. Lucchinetti's team is continuing this research to further define possible lesion patterns and the underlying mechanisms.

Extension Studies of Prior Clinical Trials

Researchers reported the results of several extension studies. These are clinical trials for treatments that were extended by months or years to determine further information on the safety or effectiveness of an MS therapy.

Other Clinical Studies

Researchers also reported results from other studies that involved experimental or FDA-approved therapies for treatment of MS disease activity and symptoms, evaluating the safety and/or effectiveness of these therapies or **combinations** of therapies. In all cases, these were reports of very small, not definitive studies. The results provide guidance for further studies, which in most cases are under way.

Several studies were presented on **mitoxantrone (Novantrone®)**, an agent approved by the FDA in 2000 for worsening forms of MS. Dr. Gilles Edan (Rennes, France) presented safety information on Novantrone in 802 people with MS, gathered by 12 MS centers in France. They found the drug to be generally well tolerated, although patients were using the drug for less than the maximum tolerated dose to avoid cardiac toxicity. Also, two patients developed acute myelogenous leukemia, a higher incidence of this type of cancer than reported in the general population. Dr. Emanuelle Le Page, a colleague, evaluated 100 individuals who had received **Novantrone and methylprednisolone** for worsening relapsing-remitting MS before taking other MS therapies. Relapse rate and

disease activity on MRI were reduced significantly in this group, and the author notes that this may indicate that Novantrone can be used before initiating other therapies in worsening relapsing-remitting MS. Further studies exploring this possibility are underway.

Dr. Douglas Jeffery (Winston-Salem, NC) and colleagues treated 10 people with worsening relapsing-remitting or secondary-progressive MS with **Betaseron and Novantrone**. In a short-term study, treatment was well tolerated, and relapse rates decreased by 74%. Dr. Daniel Mikol (Ann Arbor, MI) tested **Novantrone and dexrazoxane (Zinecard®)**, a cardioprotective agent) in 26 people, and reports that the combination is safe and tolerable. He is continuing to study this combination to determine if it will decrease the risk of cardiac toxicity associated with Novantrone.

Dr. Eva Havrdova (Prague, Czech Republic) studied **Avonex, azathioprine and low-dose steroids** in 105 people with relapsing-remitting MS, and found that the combination was tolerable and reduced the relapse rate by 56% in one year and 72% in two years.

Dr. Dean Wingerchuk (Scottsdale, AZ) found that 42% of 30 people with MS reported good or excellent improvement in fatigue levels when treated with **aspirin**, compared with 11% of the same individuals during a placebo phase. Further study is necessary to confirm findings and explore possible mechanisms.

Dr. George Kraft (Seattle, WA) and colleagues presented preliminary findings from a study of **transplantation of blood stem cells** in 26 individuals with severe, progressive MS. Twenty patients appeared to have stabilized over a short period after the procedure, but further observation is necessary to determine if stabilization will continue. The procedure has significant risks and side effects, and one death was reported in this study. More information is available in the bulletin, **“Researchers Report Modest Success Transplanting Blood Stem Cells To Treat Severe MS”**

(<http://www.nationalmssociety.org/Research-2002Apr17.asp>).

In a Society-funded project, Dr. Joonmi Oh (San Francisco, CA) and colleagues studied 47 people with MS, to determine whether

different imaging techniques looking at different parts of the brain might be useful in diagnosing and understanding the various clinical courses of MS. Looking at the corpus callosum (nervous tissue that connects the right and left sides of the brain) enabled investigators to detect nerve fiber damage in people with relapsing-remitting or secondary-progressive MS. Studying the central region of the brain was more informative in those with primary-progressive MS. This study suggests new avenues for exploring underlying differences in disease pathology of different clinical forms of MS.

(<http://www.nationalmssociety.org/Research-2002Apr23.asp>).

-- Research Programs
Department MS Society USA

54th AAN.doc

Australian team identifies protein to ease MS

The discovery of a protein that may lead to a new treatment for multiple sclerosis (MS) by protecting nerve cells from attack by the immune system has been announced by an Australian research team.

A team from the University of Melbourne, led by MS expert Doctor Trevor Kilpatrick, found the administration of a naturally occurring protein, or cytokine, reversed the loss of nerve cells in mice with the animal form of MS.

"We were able to show that the protein involved, Leukaemia Inhibitory Factor (LIF) reduced the severity of the clinical disease in animals and kept cells, which normally die off in MS, alive. "

Dr Kilpatrick says human trials are ready to go ahead but timing depends on Amrad, a Melbourne biotech company that holds the commercial rights to the research.

ABC On Line 5/6/02

The pull-out-and-keep SPOTLIGHT on MS supplement, which will appear in each MagScene, highlights current medical articles on MS in a condensed form.

The NSW Multiple Sclerosis Society is proud to be a source of information about MS. Comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

The Multiple Sclerosis Society of NSW or its servants or agents will have no liability in any way arising from material or advice that is contained in this supplement. The statements or opinions that are expressed herein reflect the views of the author(s).

Z Barron: Editor

Dr Garry Pearce: Medical Editorial Consultant, Medical Director MS Society of NSW, Specialist in Rehabilitation Medicine
ISSN 1323 4005

“GP Focus on MS” is a newsletter providing information for General Practitioners. It is published twice a year by the Multiple Sclerosis Society of NSW. It is edited by Dr. Garry Pearce, MBBS, FAFRM, FRACGP, Director of Rehabilitation, MS Society of NSW.

For your doctor to receive free regular copies of our GP FOCUS ON MS, please ask your doctor to complete the following.

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Please post to GP Focus on MS, MS Society of NSW, PO Box 1246, Chatswood, 2057 or fax to (02) 9411 1712

Page. 13 NEWS

Compiled by
Katie Booth

ILLAWARRA REGION

An information session on "Maximising Memory" will be held on Tuesday 22nd October 2002 at Corrimal Community Centre, Short St, Corrimal. Wendy Longley, Clinical Neuro Psychologist for the MS Society will be presenting the session. It will be held from 10am - 12.30pm with morning tea included. If you would like to attend, please register with Jenny Crofts, Outreach Worker for the Illawarra by phoning 42856407 by 8th October.

SOUTH COAST/GOULBURN REGION

A Country Consultation Visit has been arranged for Wednesday 14 August in Batemans Bay where MS Society specialist staff including a physiotherapist, occupational therapist and clinical nurse consultant will travel to the Bay for the day to conduct clinical assessments. Expressions of interest have been posted; unfortunately as time is limited only five people will be successful in securing a place for the day.

On Thursday August 15 an education session on **MS & Fatigue** will be run where an MS Society occupational therapist will speak on MS & Fatigue. The venue will be the Conference Room, Community Health Centre Batemans Bay. Starting time 10 am for morning tea and welcome

with presentation beginning at 10.30 am and finish time 12 noon. If you are interested in attending please contact

Barbara Whitelaw Outreach Worker South Coast/Goulburn Region

on 4285 4702 to register.

CENTRAL COAST

I was an honoured guest at the **MS Fundraising** dinner in May at the Gosford Leagues Club. It was a Gala Evening organised by David and Rachael McDonald with some 140 paying guests at \$65 a ticket. The M.C. Chris King opened with a song, then introduced Read-a-thon Manager Anne Marie Keleher and myself into the spotlight. I told the guests, donors and sponsors that I was overwhelmed by their generosity and being a person with MS for twenty years, I couldn't think of a more worthwhile cause. Entertainment was by The Society of Creative Anarchy, performing medieval dancing and mock battles.

An auction of donated luxury goods, vouchers and holidays raised over \$15,000 for MS on the night.

The Central Coast Branch Committee worked with **PwMS** at major shopping centres in June to spread MS Awareness. Over \$2,000 was raised in a raffle.

The skilled committee was re-elected on 19th June with the welcome addition of Annette Bohringer as assistant treasurer. Stalwart John Smith has held the office of treasurer since formation of this branch in 1993. Positions are President, Clem Payne. Vice Pres. Frances Pavy and Jean Smith. Secretary,

Sue Payne. Treasurer John Smith. Assistant Treasurer Annette Bohringer. Assistant Sec. Katie Booth.

The new venue for future MS Branch and PwMS Council meetings is the Central Coast Leagues Club, Gosford.

Art Exhibition and Auction

Works by accomplished artists, Steve Preston and Yianni Johns were exhibited at the Entrance Surf Lifesaving Club 8th-10th June (long weekend). Funds raised at the Auction were generously given to the central coast MS Society and The Entrance Surf Club

COUNTRY WEST New Contact Details For OUTREACH WORKER

Rhonda Pitt is the new Outreach Worker for Country West. The Molong office has been closed and a new home based office set up in Orange. Rhonda can now be contacted by:

Phone/fax: 6361 3339

Email: rpitt@msnsw.org.au

Post: PO Box 610 ORANGE
NSW 2800

Mobile phone: 0417 068 643

Rhonda works Monday,
Tuesday and Wednesday.

Katie Booth

My thought for July:

I try to take one day at a time but sometimes several days attack me at once.

Readers are invited to e-mail contributions for 'Page 13 News' to the editor of MagScene at:
pwms@msnsw.org.au
....or snail-mail to: MagScene,
PO Box 1246 Chatswood 2057

RUTH, OUR SPECIAL, AND FIESTY LADY

Ruth, (AKA Bottlebrush) as you are aware, was a very unique person. She was one of the most articulate, and also vocal, persons I have had the good fortune to be associated with. Ruth was originally from England, where she was trained as a nurse. She adopted Australia, and her wonderful carer Pat Hilton's family, as her own.

Ours was a special bond
A group of individuals thrust together with
our very own 'shadows'
We cried together, we fought, we laughed
together.
We were friends you and me.
You were our intellect, our fountain of
knowledge.
Our group, our circle of friends,
We respected you.

You were vocal, you were articulate.
You argued, you reprimanded.
You told us when we were getting too fat.
You kept us on our toes.
You cared about us Ruth.

Your own illness,
The never- ending pain, the loss of self-
sufficiency,
Never dulled your sharp, clever mind.
Your incredible strength,
Your extraordinary intellect,
Your deep, but private, belief in God
Made you unique.

Ruth, you said in your book, that you
wondered if your tears,
Perhaps like those of King David,
Would get to be stored in God's bottles.
Ruth, your precious tears were not wasted.

We are saddened because you have left us Ruth.
But we are richer for having known you.
Goodbye Miss Bossy Boots.
Goodbye dear friend.

Judith Reid
4th June 2002

Ruth was one of the founding members of the Bega Valley PwMS. She served for several years, in the beginning, as President or Secretary. She was passionate about ensuring the group functioned as a true 'Support' group and made sure that we all kept in touch with each other, particularly those who for many reasons had left the group. Woe betide anyone who didn't give, what she considered, 'true support'. Ruth was also a very active member of the local group of Australian Fellowship of Writers. She was very respected for her sharp wit and her ability as a professional writer. Her book, 'Me & MY Shadow, a book on her life with Multiple Sclerosis, was written with knowledge, humour and of course her unique wit. She had just finished the manuscript for her second book, which will be edited by her fellow writer's & friends. She loved her writing and her computer was her lifeline. Ruth has left her imprint on all of us. We will miss her but we know that she is 'up there' ordering the angels around, ensuring they are doing their jobs. We also believe that she is free of pain and walking tall.

Bega Valley PwMS.Council

MAGSCENE 'MEET'

What's this? An invitation from MS Society - LOWER MOUNTAINS / RIVERLAND Support Group and it will be for the UPPER MOUNTAINS Group in Penrith to meet Zanna Barron, Editor of MagScene. This is an ideal opportunity for us to meet a few others with the same problems and discuss a few of their concerns. Maybe we can see ways of joint collaboration. Maybe just enjoy the drive down.

It is not a long trip; in fact it would probably be a greater effort for Zanna to get there than it would be for us. Leura to Penrith even on a foggy morning with business traffic at peak hour is not always easy. When we walked in the room it was full with members and carers and the table spread with plates of food. We were all welcomed by Outreach Worker, Sharon Lee into a large group of over twenty.

Sharon introduced Zanna to everyone. At last we could all put a face to the name appearing regularly in MagScene. Zanna began with a brief history of MagScene. She started producing this magazine on a very low budget nearly twenty years ago with the help of limited staff and PwMS. It now goes bi monthly to 6000. When I was living not far from the Chatswood MS Centre, helping with labelling and stuffing envelopes was a fun few hours. Zanna showed us a number of the different layouts so we could see how things had changed. We

discussed the different items that are included in the magazine and the different interests people have. We drew very heavily on Zanna's professional experience as a journalist in the Frank Packer Group and Readers Digest before MS brought her career to an end.

While this was happening we were all munching away on cheese on biscuits, lamingtons, chocolate cake and other sweets. Donna was keeping up a steady flow of biscuits and cheese. Danny was there and of course with Mila had bought down a beautiful chocolate cake for us all to enjoy. She was also active with the hot drinks so there was a steady flow of tea and coffee for those who so wished.

Zanna's memories took us back to writing articles for the magazine. So many members over the years have contributed their own stories to MagScene. This has given an interest to individuals who told their stories. It seems as though each of us is unique. I know there is a danger that one can feel lonely and different until reading that so many others are not exactly the same, just a little different. Fascinating. There is a story in each of us and when we commit our thoughts to paper we find out more about ourselves. Therein may be a very interesting story for MagScene.

We enjoyed our morning tea and we were able to catch up with others from another area. Like those who we might have met

previously and hopefully will again. Irene used to come to meetings in Upper Mountains, Mike of course helped with organizing and I found myself comparing MS in Holland and Australia with Harry.

It was a pleasant meeting and could well be repeated; perhaps with visitors from the other side of the mountains, say once a year,....share your thoughts on this idea.

Editor

PwMS express their appreciation to Sharon Lee for all her efforts in making the day possible.

Peter Aboud, Leura

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MR WISDOMS BRAIN GAIN



That's IT ! I am going to have to select a simpler word with NO vowels for this Challenge Word, as

ACROCEPHALOSYNDACTYLI

A produced an onslaught of paper that must have denuded a whole forest !

So, to save the environment, my sanity, and a postage bill to rival the national debt, I am going to have to re-think my Challenge Word. My challenge is, can I?

I have gained some satisfaction in knowing I have driven my entrants crazy as well. Wendy Sallis, of Claymore, went completely nutty compiling her 2,183 words. Congratulations Wendy.

Christine West, of Appin, was kept awake nights (HA!) with her submission of 1,683.

Janet Goadby, of Wentworth Falls, actually attached paper to her walker and neglected sleep, her jobs, and her dogs, to pursue 1,490 words.

Now Janet, I don't mind you ignoring sleep, work, even husbands, but neglecting the dogs? ... Never!

I consulted MagScene's ex-columnist, Casey the Bichon Frise, and his partner Phoebe the Fox Terrier, and the consensus is the RSPCA should be advised if your obsessive behaviour continues.

Sue Johnston, of North Haven, ran out of time completing her 1,061 words,

Barbara Dean of Lithgow submitted 563, and Ronda Maher of Cootamundra 544. A late entry from Lorraine Mahe, of Towradgi, (you would have thought a recently retired PwMS would have plenty of time for my Challenge), submitted 1,488 words.

Your new Challenge Word is **HYPERKERATOMYCOSIS** , just for my thick skinned regulars. (Fooled you with that 'no vowel' business?)

The usual rules apply

- 1: Your listed words must be made up of four or more letters.
- 2: Use only letters from the Challenge Word.
3. No letter must be used more often than it appears in the Challenge Word.
4. No plurals, place names or proper nouns will be accepted.
- 5: And remember, it's a bigger challenge if you don't use a dictionary

.....
 ...We have some new cryptic towns for you

-
- BIBLICAL GARDEN
 - THE LARGE HILL IS AS NICE AS CAN BE
 - SHYSTERS REFUGE
 - STAND IS TAILLESS BUT HEALTHY ON THE APEX

Answers on page 20

Have you ordered your Free ID Card?

Many people with MS have requested that the Society provide an ID card. Following consultation with PwMS and Societies in other States , a card has been produced which has a photo on the front and on the



back says....

For security, the card will be numbered and laminated. The address and phone number of the MS Society is also included

There is no cost other than the provision of a black and white or colour photo.

If you would like to order a card, please forward a **stamped, self-addressed envelope and a "tiny" (approx 3x3 cm.)** or an old Drivers License photograph of yourself to:

MS Society ID CARD

PO Box 1246

CHATSWOOD NSW 2057

WILMA HAIGH



Wilma with Annette

I would like you all to meet Wilma Haigh, my husband's aunt. Wilma and her husband Noel have just completed their seventh MS bike ride. They first took part in the big rides in 1996 after they were inspired by the variety of ages of the riders taking part in an earlier ride in 1992 in which her son Malcolm participated. Wilma thought that if the ride came close to Orange she would take part. So she started peddling and in 1996

undertook the Albury to Bathurst ride and hasn't stopped since.

Wilma this year raised a total of \$10,405.60 for the MS Society and over the last seven years has raised an incredible \$45,792.55. I would like to thank Wilma and Noel on behalf of all PwMS for all their efforts in raising money for the MS Society.

Wilma is a wonderful person who, after my diagnosis in October 1998, was even more determined to continue her bike rides and fund raising to help find the cause and cure of this mysterious disease. Wilma and Noel are in their early sixties and are already looking forward to the next ride. If you live in the Orange area and see Wilma out and about be sure to say G'day, she would only be too happy to stop and have a chat.

Cheers Annette Ridley



Wilma and Noel on the recent Manilla to Walcha Ride

NEWLY DIAGNOSED AND FAMILY INFORMATION SESSIONS

Monday, 19 August, 6:30 – 8:30pm

The Studdy MS Centre, Lidcombe

TEL: 02 9646 0600 for details

Wednesday, 23 October, 7:00 – 9:00pm

Central Coast Region

TEL: 02 4977 3330 for details

Wednesday 30 October, 6:30 – 8:30pm

Northern Region MS Service, Chatswood

TEL: 02 9411 4522 for details

Information Telephone Conferences

Tuesday, 3 September, 7:30 – 8:30pm

Telephone link-up in country areas

TEL: 02 9411 4522 for details

S.T.E.P.S to Well Being

Fighting Fit

(For people recently diagnosed)

Tuesday, 20 August, 7:00 – 9:00pm

The Studdy MS Centre, Lidcombe

TEL: 02 9646 0600 for details

Preventing Falls

August, to be confirmed

Northern Region MS Service, Chatswood

TEL: 02 9422 4522 for details

Diet & Nutrition

(For people recently diagnosed)

Telephone link-up in country areas

Tuesday, 17 September, 7:30 – 8:30pm

TEL: 02 9411 4522 for details

Bladder & Bowel Troubles

Saturday, 28 September, 10:00am – 12:00pm

Southern Region MS Service, Kogarah

TEL: 02 9540 4544

Staying Positive

(For people recently diagnosed)

Monday, 21 October, 7:00 – 9:00pm

Southern Region MS Service, Kogarah

TEL: 02 9540 4544 for details

Maximising Memory

Tuesday, 22 October, 10:00am – 12:00pm

Illawarra Region, Corrimal

TEL: 02 4285 6407 for details

GOING THE WHOLE WAY FOR MULTIPLE SCLEROSIS



When John McDermott takes on a project he doesn't do things by half.

Thirty four year old occupational therapy student Mr. McDermott has embarking on a 2,818 km bike ride from Uluru in central

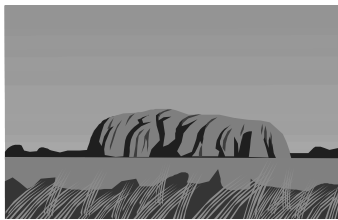
Australia to Sydney on a penny-farthing bike to raise money for multiple sclerosis research. John has been inspired to undertake his marathon ride by a friend who has MS.

"Riding the penny farthing is a small representation of the difficulties many people with MS have in carrying out their daily activities," he said.

There is no known cure for Multiple Sclerosis and the cause is not known

It is the varying combination of symptoms that makes the condition particularly difficult to support within the community and which drives the need for specific support services.

John left his base at Uluru on June 30 and expected to be arriving at the MS Society of New South Wales headquarters on August 9.

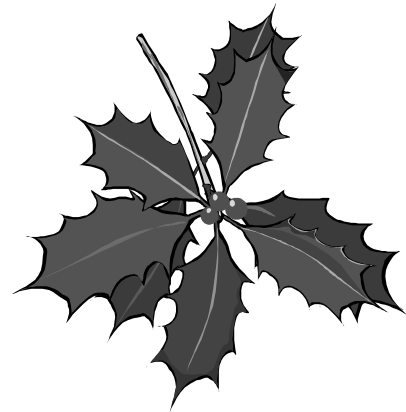


John's friend, Andrew who is 33, was diagnosed with MS when he was 19.

"I hope with this ride that I can raise media attention which will create sponsorship interest which in turn will create funding for the MS Society. I want all the money I raise to go towards research into the cause of this disease," he said.

To make a donation to support John's epic journey people are invited to telephone the MS Society on 1800 287 367 or John McDermott Telephone :0404 493 151

Christmas 2002



Here's your opportunity to get in early for Christmas. In this MagScene we have placed a colourful copy of our "hot off the press" brochure and order form.

I've seen this year's selection of eight attractive cards and I believe that they are the best we've featured, both in design and price wise.

In buying your Christmas cards from the MS Society you are assisting us to provide essential and relevant care and to fund research to benefit PwMS.

Did you know that the MS Society is the only organisation which provides specialised programs for PwMS?

Order your Christmas cards now by fax, phone or mail

SCIENTIFIC MEETING

MS Australia has announced the details of the next Scientific Meeting – Progress in Multiple Sclerosis Research, to be held on 9th – 11th October 2002 at the Centenary Institute in Sydney.

Part of MS Awareness week was the MS Regatta held for the sixth time this year and once again some 70 people with MS, their carers and supporters took part in the sailing on Sydney harbour.

Convenor of the regatta, Society Recreation Worker Leslee Cameron, says sailing is a sport which is particularly appealing to people with multiple sclerosis.

“Gliding across the water on a boat can give people with MS a sense of freedom which they might not otherwise have,” she says.

“Sailing is as much a sport of the mind as it is of physical mobility and strength, so people with physical disabilities are often able to adapt to their surroundings on a boat equally as well and quickly as those who don’t have a physical disability,” she said.

Ms Cameron said that for the sixth year Ausail Sydney Yacht Charters had donated their Catalina Yachts together with skippers and the Surf Life Saving Association (Northern Beaches) had provided a surf rescue boat to make the day out on the water by people with MS particularly memorable.

“We are particularly grateful to Ausail, The Royal Sydney Yacht Squadron and the Surf Life Saving Association for their continuing and invaluable contributions towards making this day the success it was,” she said.

However the sailing star of the fleet was undoubtedly the yacht Aspect

Computing. (illustrated)

The 16 meter yacht was a special guest at the regatta and is sailed by Sailors with disabilities (SWD), a unique group of people who have a diverse range of disabilities, gathered together to participate in sailing projects with the idea of showing others what people with disabilities can achieve.



The program started in 1994 with the goal to compete in the 50th Sydney-Hobart race. Since then they have competed in 5 Sydney-Hobart races, achieving 9th across the line and winning their division in the tough race of 1998. Other achievements include a 3rd in division in the 1995 Sydney - Hobart race, won the SCOR series at Mooloolaba in 1997 and the line honours trophy for the Clipper Cup at Port Douglas in 1997.

The regatta was won by the 40 foot Catalina “Naia” crewed by clients and staff from Southern Region MS service who were presented with the Royal Sydney Yacht Squadron MS Regatta Trophy, by Vice Commodore Rex Harrison of RSYS

Another highpoint of the week was the National closed circuit television program. The MS Society of NSW, in conjunction with the Rural Health Education Foundation, broadcast the program featuring Australian research leaders, Professor Claude Bernard, Professor Graham Stewart, Professor John Pollard and Dr Jane Frith. Professors Bernard and Stewart focused their remarks on research into the cause of MS and Professor Pollard and Dr Frith concentrated on the treatment aspects of the disease.

MS Awareness Week would not have been possible without the very generous support of the Society’s Branches, Support Groups, the Country Professional network and the Society’s staff.



A Report from the city

We, that is Garry and I, are now in the middle of skyscrapers in the Sydney city. Quite a change from the green shrubbery of Mowbray Road in Chatswood. Garry travels from Dee Why to pick me up at Killarney Heights on the days we come into the office in the city – quite a long journey and traffic!!! traffic!!! traffic!!! We will be pleased to return to Chatswood office, which is anticipated to be late August.

On a sad note: an MS friend died early June. I met Ruth Bayne in Lidcombe Centre years ago when we were staying there for rehab. We became instant friends and remained so.

You may recall the wonderful stories of Myrt and Bottlebrush that appeared in MagScene some years ago, “Australian spelt as she is spoken”.

Ruth was insatiable for knowledge about MS and used her very medical background in nursing to gather enough information about MS, which coupled with her life experiences as a Matron in many hospitals culminated in a book that she called *Me and My Shadow*. Ruth trusted me with her first drafts of the book and we spent many hours discussing the best way to say things about MS. Please see a tribute to Ruth on page 14 of this issue.

We are proud to be associated with Robyn Smith who prepared the article on chronic pain in MS, also featured in this issue. Robyn has certainly

added to the credibility of the NSW Society.

On the subject of chronic pain, which both Garry and I have, we can categorically confirm that what Robyn says about using the mind to minimize it,- it works!. We find that one of the best ways is to make yourself busy. This tends to take your mind of that burning, that ache, that electric shock, that tingling etc. etc.

Well, that’s it for now.

Zanna Barron, Editor

The answers to Cryptic place names on page 16 are 1. Eden 2. Mount Pleasant 3 Crookhaven 4. Stanwell Tops

Deadline for Sep /Oct issue is

30th August 2002

MS INFORMATION LINE Freecall 1800 042 138

Mon-Fri 9:00am to 5:00pm. An info line only – Not a crisis line.

MagScene

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Technical / Editorial Consultant:

**For People with MS NSW
P O Box 1246
CHATSWOOD 2057**

**Garry Anderson
Email: garrya@msnsw.org.au**

**Phone: (02) 9287 2929
Fax: (02) 9287 2987**

**Design: SCANDiA
Email: scandia@ozemail.com.au**

**Proof Reader: Wal Simmonds
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